DOCUMENT RESUME

ED 327 016 EC 232 663

TITLE	The Virginia Agenda for Prevention of Developmental Disabilities in the 1990's. Recommendations.
INSTITUTION	Action for Prevention, Inc., Richmond, VA.; Virginia Commonwealth Univ., Richmond. Virginia Inst. for Developmental Disabilities.
SPONS AGENCY	Virginia State Dept. of Mental Health and Mental Retardation, Richmond. Developmental Disabilities Unit.
PUB DATE	Dec 89
CONTRACT	VA-MH-MR-89-07
NOTE	49p.; For a related document, see EC 232 664.
PUB TYPE	Viewpoints (120) --
EDRS PRICE	MF01/PC02 Plus Postage.
DESCRIPTORS	*Delivery Systems; *Developmental Disabilities; Educational Needs; Elementary Secondary Education; *Genetics; *Perinatal Influences; Preschool Education; *Prevention; Public Policy; Research Needs; Social Action; State Standards
IDENTIFIERS	*Virginia

ABSTRACT

Action for Prevention, Inc., in collaboration with the Virginia Institute for Developmental Disabilities, instituted a project to refine and update the 1983 Virginia Act Agenda for the prevention of developmental disabilities. This document presents recommendations from the project's four Task Forces charged with the responsibility of evaluating progress in developmental disability prevention in Virginia since 1983 and establishing new priorities for prevention of developmental disabilities for the 1990's. Recommendations are organized in sections on genetics, perinatal influences, early childhood, and school age/adolescence. A subsequent section categorizes the recommendations into the areas of service, education, and research. This section is coded to indicate which recommendations have been standing since 1983, which recommendations suggest legislation, and which recommendations are being addressed currently in the public sector and where that action is taking place. A list of the members of each task force is included. (JDD)

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ACTION FOR PREVENTION, INC.

ED327016

THE VIRGINIA AGENDA FOR PREVENTION OF DEVELOPMENTAL DISABILITIES IN THE 1990'S

RECOMMENDATIONS

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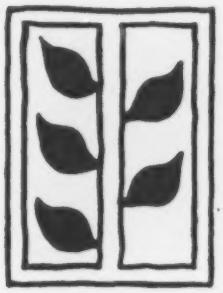
VIRGINIA INSTITUTE FOR DEVELOPMENTAL DISABILITIES

The Virginia Institute for Developmental Disabilities (VIDD) is Virginia's only university affiliated program working toward the independence, health, productivity, and community integration of people with developmental disabilities. The institute was formed in 1985 through a grant from the Administration on Developmental Disabilities to Virginia Commonwealth University. It is a part of a nationwide network of over 50 university affiliated programs providing interdisciplinary training, technical assistance, exemplary services, research, and information dissemination.



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ACTION FOR PREVENTION, INC.

Action for Prevention, Inc. (AFP) is a voluntary, non-profit organization which promotes the prevention of such developmental disabilities as mental retardation, autism, cerebral palsy, spina bifida, deafness, blindness, epilepsy, and juvenile rheumatoid arthritis. Action for Prevention, Inc., as a coalition of parents, professionals, individuals and organizations, is committed to publicizing what is known about the prevention of developmental disabilities, encouraging further research, and most importantly, insuring that the knowledge is put to use in Virginia.

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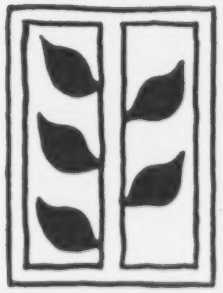

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THE VIRGINIA AGENDA FOR PREVENTION

OF DEVELOPMENTAL DISABILITIES IN THE 1990'S

RECOMMENDATIONS

Action for Prevention, Inc.

December, 1989

This document was prepared for Action for Prevention, Inc. by the Virginia Institute for Developmental Disabilities at Virginia Commonwealth University in Richmond, Virginia. Funding for this document's preparation and publication was from the federal Developmental Disabilities Basic State Grant Funds, administered by the Developmental Disabilities Office of the Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services in response to funding priorities established by the Virginia Board for Rights of the Disabled.

Grant Award ID Number
VA MH MR, 89-07

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INTRODUCTION

A developmental disability means a severe, chronic disability of a person which is manifested before the age of 22. It is attributable to a mental or physical impairment or combination of such and is likely to continue indefinitely. Further, it results in substantial functional limitations in three or more of the following areas of major life activity: (a) self care; (b) receptive and expressive language; (c) learning; (d) mobility; (e) self-direction; (f) capacity for independent living; and (g) economic self-sufficiency. There are approximately 80,000 persons in Virginia who have one or more developmental disabilities.

There are many known and suspected causes of developmental disabilities and most occur primarily in the early periods of life. Before conception and during pregnancy, the parents' genetic systems, environmental contaminants, diseases and infections, and social conditions affect reproduction and fetal development. Specifically, organic conditions such as chromosomal abnormalities, genetic abnormalities, congenital infections, or maternal diseases are causes of developmental disabilities. Environmental conditions such as contaminants or radiation as well as use of alcohol or drugs also are known causes. Finally, social conditions such as adolescent pregnancy, poverty or malnutrition can be causes.

At birth, there are complications of delivery and conditions of the newborn (such as prematurity or low birth weight) that are known to affect the brain and to increase the risk of impairment. During childhood, poor nutrition, diseases, infections, accidental poisoning, lead poisoning, abuse and neglect and accidents may result in developmental disabilities.

The cost of developmental disabilities is high. Added to the cost of care and maintenance of those unable to care for themselves, there is the loss of potential contributions to the economy. Actual dollar cost per person cannot be estimated but we do know that the collective efforts of federal and state governments is in the billions.

Knowledge on prevention of developmental disabilities is growing and some conditions have been nearly eliminated: congenital rubella, retardation from phenylketonuria and congenital hypothyroidism, neonatal jaundice and measles encephalitis. Other conditions such as morbidity from prematurity have been reduced. Further, significant efforts are underway to address other conditions such as neural tube defects, fetal alcohol syndrome, prenatal screening, lead poisoning and injuries to the brain from automobile accidents. Conservative estimates indicate that as much as 50 percent of developmental disabilities could be prevented.

Through research, it is increasingly evident that prevention can work and it is significantly less expensive that remediation and/or maintenance. Further, there is a growing constituency to

encourage and implement successful prevention. At a time when society is witnessing the diminishing of resources and an increasing population with social complexity, it would seem a priority must be to "wisely invest" increasingly limited resources into protecting the most precious resources- humans- by preventing a condition before it occurs.

Federal efforts for prevention of developmental disabilities are important, but the level of activity most critical to success is in the states. Virginia was an early leader in addressing prevention of developmental disabilities. In the early 1970's, there was a series of activities and actions taken in Virginia that generated an increasing awareness of the potential for the prevention of disabilities and an increasing desire to see that prevention was undertaken in a more systematic and effective manner.

The fruit of this work was the 1983 Virginia Mental Retardation Developmental Disabilities Prevention Conference which brought together over 400 persons from across Virginia and the nation who were committed to the prevention of developmental disabilities and mental retardation. For three days, the conference participants discussed and debated issues surrounding prevention of disabilities. More importantly, they went beyond causes of disabilities to center on practical prevention strategies. The Williamsburg prevention conference generated over 125 recommendations known as the The Virginia 1983 Action Agenda. That document pointed the way for Virginia to begin a coordinated effort to reduce the incidence of developmental disabilities.

The prevention conference was jointly sponsored by the Virginia Association for Retarded Citizens, the Virginia Department of Mental Health and Mental Retardation, the Virginia Developmental Disabilities Planning Council and Virginia Commonwealth University. The conference reflected a degree of interagency cooperation that was highly unusual and boded well for future prevention efforts.

Following the conference, Action for Prevention, Inc. was formed and steps were initiated to establish a University Affiliated Program at Virginia Commonwealth University, subsequently the Virginia Institute for Developmental Disabilities. In addition, many of the recommendations of The Virginia 1983 Action Agenda were addressed and further work was done on the Action Agenda in 1985.

Then, in the fall of 1986, Action for Prevention, Inc. (AFP) entered into a collaboration with the Virginia Institute for Developmental Disabilities (VIDD) at Virginia Commonwealth University. The project began the process of refining and updating The 1983 Virginia Action Agenda for the prevention of developmental disabilities in order to update, expand and refocus Virginia's prevention activities in the area of developmental disabilities. The project also organized and established a system for collecting prevention indicator data and for analyzing prevention indicator

data and policy in Virginia in order to monitor and evaluate progress on the Action Agenda over time. Further, the project developed a repository of resource materials and publications on prevention of mental retardation and developmental disabilities.

The project was supported by federal Developmental Disabilities Basic State Grant Funds, administered by the Developmental Disabilities Office of the Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services in response to funding priorities determined by the Board for the Rights of the Disabled (Virginia's State Planning Council for Developmental Disabilities).

To implement the project, Dr. Howard Garner, Director of VIPP, acted as Director and a full-time Prevention Policy and Research Associate, Elizabeth Campbell, was appointed to the staff of VIPP to work on the project. In order to achieve the main goal of updating and refining the Action Agenda, the project formed a Task Force in each of the following four areas: Genetics, Perinatal, Early Childhood, and School Age/ Adolescence. With approximately 150 professionals participating, these Task Forces were comprised of ACP members along with representatives of related agencies and organizations. The Task Forces were charged with the responsibility of evaluating progress in developmental disability prevention in Virginia since 1989 and establishing new priorities for prevention of developmental disabilities for the 1990's.

Each Task Force met twice in the winter of 1989, doing a significant amount of gathering and reviewing information prior to and following each meeting. After providing each other with information about the status of issues raised in 1989, each Task Force developed a list of prioritized recommendations for the 1990's.

The four Task Forces generated, collectively, over a hundred recommendations. Generally, they suggest new and expanded services, request public and private agency coordination, call for legislative or executive action, highlight public and community education needs and point to research directions for 1990's.

This document is organized as the Task Forces were and presents the recommendations as follows:

.SECTION I = Genetics
.SECTION II = Perinatal
.SECTION III = Early Childhood
.SECTION IV = School Age/Adolescence
.SECTION V is divided into three subsections which list the recommendations of the four Task Forces in three categories: service recommendations, education recommendations, and research recommendations.

Further, this section is coded to indicate which recommendations have been standing since 1989, which

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SECTION I

GENETICS TASK FORCE

GENETICS-RECOMMENDATIONS

1. Mandate and fund prenatal maternal serum alpha fetoprotein (MSAFP) testing for neural tube defects (anencephaly and spina bifida) to include follow-up of abnormal tests.

2. Mandate and fund a masters level genetic counseling program to address manpower needs in Virginia. This should include funding and FTEs for at least three faculty positions and student stipends which require students to provide services in the state for a specified time.

3. Fund Virginia Congenital Anomalies Reporting and Education System (VACARES) as a line item in the state budget. This should include initial funding for at least five FTEs for additional manpower needs and continued evaluation for the program.

4. Fund a centralized state program to perform molecular genetic testing (prenatal and carrier) for common genetic diseases such as sickle cell anemia (SCA), cystic fibrosis (CF), Duchenne muscular dystrophy (DMD), Huntington disease (HD), Fragile X Syndrome, and neurofibromatosis (NF).

5. Fund a full-time health educator at each state genetic center to educate a variety of audiences about genetic disorders. This funding must include educational materials.

6. Fund a program for education of health professionals and patients about the risk of birth defects resulting from such maternal conditions such as diabetes, seizure disorders, and metabolic disorders.

7. Establish a state fund of $50,000 (statewide) for the first year to perform diagnostic testing for very rare (orphan) genetic diseases. Effort should include a needs assessment.

8. Mandate and fund newborn screening programs for disorders such as Duchenne muscular dystrophy (DMD), cystic fibrosis (CF), AIDS, when such tests are demonstrated to be valid and effective.

9. Fund post-doctoral training in clinical genetics at each state human genetics center.

10. Include human genetics education materials as a component of Family Life Education curricula.

11. Mandate follow-up and repeated newborn screening for infants screened before the age of 36 hours.

12. Implement the Mid-Atlantic Human Genetics Network's (MARGHN) and Congress of Regional Networks' (CORN) recommendations for proficiency testing and quality assurance of genetic diagnostic labs.

13. Fund a pilot study of neonatal screening for congenital adrenal hyperplasia (CAH) to be conducted by the state laboratory.

14. Fund a one half FTE position at each genetic center to coordinate DNA testing.

15. Fund genetics centers for ancillary diagnostic tests such as radiologic, ultrasound and clinical chemistry.

16. Improve phenylketonuria (PKU) education and follow-up directed toward both health professionals and female patients, especially with regards to risk to offspring from maternal PKU.

17. Fund a teratogen information and research program.

18. Mandate hazardous labelling of teratogens such as alcohol and tobacco products and implement a tax assessment on those products with revenues being used to support genetic services and education.

SECTION II

PERINATAL TASK FORCE

PERINATAL-RECOMMENDATIONS

1. Expand services for pregnant women: increase funding for the Baby Care Program within Medicaid and mandate third party payment for prenatal care to include the services provided under Baby Care; improve eligibility determination and location for Baby Care services; fund adequate transportation and care coordination; expand the Resource Mothers programs.

2. Change policy to allow additional use of nurse practitioners, certified nurse midwives, and physicians' assistants in perinatal care delivery.

3. Fund preconceptional education and treatment programs, included with Title X/State Family Planning money, to discourage the use of any addictive substances and to encourage cessation from substance use prior to conception.

4. Support coordinated statewide data collection regarding sexually transmitted diseases and pregnancy and identify current practices of prenatal screening for infections in private, public, and academic settings.

5. Increase funding for the Women, Infants, and Children (WIC) Program, including the use of formula rebate programs, and publicize this program widely.

6. Provide education and incentives to all perinatal health care providers to screen all pregnant women for high risk conditions which may affect pregnancy outcome, including infections, substance use, inadequate nutrition, sexual and physical abuse, environmental stress, health problems.

7. Fund adequate evaluation of Family Life Education throughout the state and identify and promote the replication of successful curricula and programs.

8. Promote contraception education with emphasis on teenage males and their responsibilities for pregnancy prevention and for their children.

9. Support the Virginia Perinatal Association's Preterm Birth Prevention Program statewide.

10. Support the presence of professionally trained school nurses in every school, at least part time, with access to comprehensive health services.

11. Provide home visits for postpartum women.

12. Offer HIV antibody testing and counseling to all high risk women during, and preferably prior to pregnancy, through substance abuse treatment centers, STD (sexually transmitted diseases) clinics, family planning clinics, and prenatal clinics.

13. Determine the extent of follow-up of women negative on testing for rubella antibodies and encourage immunization postpartum.

14. Determine the status of testing for hepatitis B and support universal testing and treatment of newborns.

15. Encourage marketing by local health departments of availability of free pregnancy testing and preferred sources of pregnancy test counseling.

16. Expand availability of ultrasonography to 1984 NIH (National Institute of Health) recommendations.

17. Ensure adequate attention to developmental disability prevention in components of Family Life Education (FLE).

18. Support specific FLE curriculum regarding fetal effects of substance use and abuse beginning in grades four, five, and six.

19. Establish smoking cessation programs designed specifically for pregnant women in at least 50 percent of health districts by 1992.

20. Require alcohol warning posters focusing on fetal alcohol effects displayed prominently in retail outlets for alcohol sale (stores, restaurants).

21. Support the Nutrition Intervention Project and sufficient FTEs for health department nutritionists.

22. Provide prenatal vitamins to all pregnant women.

23. Support the Infant Death Study and use of the study to plan service delivery and education to reduce low birth weight and preterm births.

24. Supports regionalisation of perinatal and high risk obstetric services while ensuring universal access to necessary care.

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EARLY CHILDHOOD - RECOMMENDATIONS
Sub Section II

1. Support statewide legislation requiring inspection and abatement of properties and that children not be returned to property until abatement is achieved. Further, implement statewide system for reporting lead poisoning and for implementing lead screening for all children five years and under to start at six months with subsequent testing yearly. Further, implement periodic screening for children at-risk (a minimum of 4 times a year).

2. Mandate training for professionals and persons, eg. child protective service workers and foster and adoptive parents, working with or caring for children to: (a) enable them to identify child abuse and neglect, including risk factors; and (b) meet the special needs of children who have been abused and neglected.

3. Provide a broader array of services for known or at risk families to prevent child abuse and neglect and include such areas as: employment, day care, housing and homemaking and/or parenting skills.

4. Compile and summarize empirical evidence regarding predictors on: (a) dysfunctional parenting skills, (b) relationship between dysfunctional parenting skills and developmental disabilities, and (c) degrees of effectiveness of various intervention approaches.

5. Tax leaded gas to the price of non-leaded gas with the proceeds going to lead poisoning prevention and treatment.

6. Conduct a public awareness campaign to include law enforcers, health professionals, legislators and social service professionals that addresses:

   (a) nature of the problem of lead poisoning,
   (b) need for lead screening, and
   (c) availability of lead screening.

7. Develop a broader definition of child abuse and neglect that appropriately uses the concept of risk: eg. adolescent parents, developmental disability parents and parents of chronically ill children.

8. Plan comprehensive treatment for children with lead poisoning to include:

   (a) developmental assessment,
   (b) nutrition,
   (c) hospitalization, and
   (d) therapy.

9. Provide all child abuse victims with assessment and access to treatment with follow-up services.

10. Establish comprehensive lead screening components in all health districts within one year after it goes into effect.

11. Give families experiencing lead poisoning priority for public housing.

12. Recommend evaluation of prenatal and at-birth screening for lead poisoning.

13. Coordinate (at the state level) child care centers' resources for nutritional care of children with developmental disabilities affecting their ability to consume an adequate diet.

14. Conduct a public awareness campaign on relationship between the child abuse and neglect and child development.

15. Mandate foster parents and adoptive parents to be informed of <u>any founded</u> episodes of child abuse, including sexual abuse.

EARLY CHILDHOOD - RECOMMENDATIONS
Sub Section III

1. Amend the current seat belt legislation to require "ANY" person, not just front seat passengers, to wear a seat belt.

2. Amend the current seat belt legislation to read "PRIMARY OFFENSE" (for non compliance) rather than secondary offense. Add to the legislation that "fines are to be used to defray court costs and/or child restraint public education".

3. Encourage the adjustment of child restraint public education to include proven behavior modification programs.

4. Initiate research to identify the incidence of morbidity in relation to unintentional injury (specifically, rate of incidence of unintentional injury among developmental disability population; rate of unintentional injuries among children with developmental disability parents; rate of unintentional injuries resulting in developmental disabilities).

5. Explore the possibility of using the Good Samaritan Act to limit liability of child restraint loaner programs as well as manufacturers whose products meet legal standards.

6. Develop and/or support legislation to include HIB vaccine with other vaccines required for school entry.

7. Designate regional poison control centers to be identified by the Virginia Health Department. Ensure those centers provide primary prevention of child poisonings and outreach education. Ensure outreach education includes efforts 1) to reach every family with young children, 2) to increase recognition of poison hazards, 3) to make poison control center readily accessible, 4) to place syrup of ipecac in each home and 5) to stress dangers of prenatal exposure to toxins in general and carbon monoxide in particular.

8. Initiate public and professional education programs which recognize unintentional injury as a leading cause of death and disability by emphasizing primary

prevention of unintentional injury in children.

9. Initiate consistent legislation that sets minimum standards for pool and playground areas built and/or maintained by local departments of parks and recreation, local school systems and day care and preschool centers. Suggest that the Virginia Health Department be the lead agency.

SECTION IV

SCHOOL AGE/ADOLESCENCE TASK FORCE

SCHOOL AGE/ADOLESCENCE-RECOMMENDATIONS

1. Expand the study of the validity of programs directed towards prevention of risk taking behaviors such as substance abuse. Such programs include decision-making skills, role modeling, and peer educators. Expand and continue to fund those programs with proven validity.

2. Promote comprehensive and accessible parent educational programs which help parents understand childhood development in order to promote children's healthy sexuality and prevent substance abuse, childhood injury, child abuse, and risk-taking behaviors. Establish local or regional resource centers for parents with appropriate information using understandable language.

3. Establish and enforce, with lead by the Virginia Department of Education, minimum standards for health services in the schools. Require qualified nursing personnel in all schools in ratios which conform to national standards.

4. Support and evaluate data collected in the Virginia Board of Education's Family Life Education mandate. Emphasize improved training of professionals/ teachers in how to teach all aspects of Family Life Education.

5. Encourage the Virginia Department of Health, Virginia Department of Education and Virginia Department of Transportation to develop programs and legislation aimed at the prevention of head injury especially in children and adolescents. Such programs would be focused on the use of bicycles, ATVs, skateboards and mopeds as well as playground injuries.

6. Make primary health care facilities accessible to all teens including attention to physical and mental health needs.

7. Establish a suicide/crisis program in each school system to provide support, intervention, and prevention services for students, teachers and families. Train staff and personnel for such programs in youth suicide and base the training on valid research data in reference to the National Suicide Center.

8. Make age-appropriate programs for supervision of children available and accessible (funding, transportation, etc.) for those families needing them. Involve public and private resources in implementation and focus on both educational and recreational needs.

9. Enforce the Virginia Department of Education's certification standard requiring trained CPR/First Aid providers in each school and expand it to include training for all school personnel.

10. Establish and enforce minimum standards by the Virginia Departments of Health and Education for prevention of sports and playground injuries in schools and the community.

11. Train teachers, service providers and all other persons with direct contact on working with children who have suffered child abuse.

12. Ensure that all teachers receive a certain number of hours in special education training initially and as a prerequisite for future teacher certification. This should be required for certification and recertification of all teachers.

13. Mandate for all localities multidisciplinary teams whose focus is to include case consultation and coordination of assessments, treatment, and follow-up services for child abuse/neglect.

14. Mandate a parenting course for high school graduation requirements.

15. Develop more education and service programs stressing male involvement and responsibility in all reproductive issues.

16. Develop special programs for children who are mentally retarded in regard to reproductive issues with the lead by the Virginia Department of Education.

17. Develop public awareness programs and offer motivational programs in order to promote an understanding of misuse of legal and illegal substances and to change behavior. Include programs for substance abusing parents to assist them in breaking the cycle.

18. Train all persons providing services to teens on the developmental stages and thought-process of teenagers.

19. Encourage religious institutions to provide family life education within their programs.

20. Encourage use of Child Study Teams with input of teachers, guidance, special education, etc., as vehicle for early intervention for children with problems. Encourage intense language programs in kindergarten. Encourage heterogenous grouping of students.

21. Encourage Child Study Teams to keep minutes of their meetings with log system of educational strategies used for students with problems.

22. Encourage local educational authority to improve instructional strategies via regional State Department of Education workshops and visitations of model school divisions.

23. Encourage ongoing communication and cooperation between special education teachers and regular teachers in order to improve the planning of educational services for developmentally disabled or high risks students.

24. Encourage individualized instruction for all students in least restrictive environment; encourage utilization of research dealing with instructionally effective schools.

25. Retain the behind the wheel component of driver's education.

26. Encourage the Virginia Department of Youth Services to provide appropriate family life education for <u>all</u> of its clients.

27. Continue to support the Statewide Systems Project for mainstreaming.

28. Promote school breakfast programs.

SECTION V

RECOMMENDATION CATEGORIES

RECOMMENDATION CATEGORIES

This section lists the recommendations of all four Task Forces in three categories: Service, Education, Research. Some are listed more than once. In addition, the priority rank has been retained by Task Force. Further, they are coded for following:

L = suggests legislative mandate/review.

'83 = long standing since 1983 Agenda.

CP = similar recommendation is made in, 1990 - 92 Comprehensive Plan for Virginia, Office of Prevention, Promotion, Library Services, VA Department MH/MR/SAS.

MRP = similar recommendation is made in VA Department MH/MR/SAS: A Plan for Prevention Services (Phase I: Prenatal to age 18) 1988.

MCH = similar recommendation is made in Maternal and Child Health Plan 1988 - 1994, Division of Maternal and Child Health, VA Department of Health.

SERVICE RECOMMENDATIONS

GENETICS:

1. Mandate and fund prenatal maternal serum alpha fetoprotein (MSAFP) testing for neural tube defects (anencephaly and spina bifida) to include follow-up of abnormal tests.

2. Mandate and fund a centers level genetic counseling program to address manpower needs in Virginia. This should include funding and FTEs for at least three faculty positions and student stipends which require students provide services in the state for a specified time.

4. Fund a centralized state program to perform molecular genetic testing including (prenatal and carrier) for common genetic diseases such as sickle cell anemia (SCA), cystic fibrosis (CF), Duchenne muscular dystrophy (DMD), Huntington disease (HD), Fragile X Syndrome, and neurofibromatosis (NF). MCH (pg. 38)

7. Establish a state fund of $30,000 (statewide) for the first year to perform diagnostic testing for very rare (orphan) genetic diseases. Effort will include a needs assessment.

8. Mandate and fund newborn screening programs for disorders such as Duchenne muscular dystrophy (DMD), cystic fibrosis (CF), AIDS, when such tests are demonstrated to be valid and effective.

11. Mandate follow-up and repeated newborn screening for infants screened before the age of 36 hours.

12. Implement the Mid-Atlantic Human Genetics Network's (MAHGHN) and Congress of Regional Networks' (CORN) recommendations for proficiency testing and quality assurance of genetic diagnostic labs. MCH (pg. 38)

14. Fund a one half FTE position at each genetic center to coordinate DNA testing.

15. Fund genetics centers for ancillary diagnostic tests such as radiologic, ultrasound, and clinical chemistry.

10. Mandate consistent labelling of beverages such as alcohol and tobacco products and implement a tax assessment on those products with revenues being used to support genetic services and education. *##

PREGNANCY

1. Expand services for pregnant women: increase funding for the Baby Care Program within Medicaid and mandate third party payment for prenatal care to include the services provided under Baby Care; improve eligibility determination and location for Baby Care services; fund adequate transportation and case coordination; expand the resource Mothers program. *##

2. Change policy to allow additional use of nurse practitioners, certified nurse midwives, and physicians' assistants in prenatal care delivery.

3. Fund preconception education and treatment programs, included with Title X/State Family Planning money, to discourage the use of any additive substances and to encourage cessation from substance use prior to conception. *##

4. Increase Funding for the Women, Infants, and Children (WIC) Program, including the use of formula rebate programs, and public-use file program widely. *##

10. Support the presence of professionally trained school nurses in every school, at least part time, with access to comprehensive health services.

11. Provide home visits for postpartum women.

12. Offer HIV antibody testing and counseling to all high risk women during, and preferably prior to pregnancy, through substance abuse treatment centers, STD (sexually transmitted diseases) clinics, family planning clinics, and prenatal clinics.

13. Determine the extent of follow-up of women negative on testing for syphilis antibodies and encourage immunization promptness.

14. Determine the effects of testing for hepatitis B and support universal testing and treatment of newborns.

[illegible]

[illegible]

[illegible]

[illegible]

homemaking and/or parenting skills. CP (pg. 40)

5. Tax leaded gas to the price of non-leaded gas with the proceeds going to lead poisoning prevention and treatment. *#1

7. Develop a broader definition of child abuse and neglect that appropriately uses the concept of risk: eg. adolescent parents, developmental disability parents and parents of chronically ill children.

8. Plan comprehensive treatment for children with lead poisoning to include:

   (a) developmental assessment,
   (b) nutrition,
   (c) hospitalization, and
   (d) therapy.

9. Provide all child abuse victims with assessment and access to treatment with follow-up services.

10. Establish comprehensive lead screening components in all health districts within one year after it goes into effect. CP (pg. 61)

11. Give families experiencing lead poisoning priority for public housing.

12. Recommend evaluation of prenatal and at-birth screening for lead poisoning. CP (pg. 61)

13. Coordinate (at the state level) child care centers' resources for nutritional care of children with developmental disabilities affecting their ability to consume an adequate diet.

15. Mandate foster parents and adoptive parents to be informed of any founded episodes of child abuse, including sexual abuse.

EARLY CHILDHOOD-SCH GROUP III:

1. Amend the current seat belt legislation to require "ANY" person not just front seat passengers, to wear a seat belt. CP (pg. 60)

2. Amend the current seat belt legislation to read "PRIMARY OFFENSE" (for non compliance) rather than secondary offense. Add to the legislation that "fines are to be used to defray court costs and/or

child restraint public education". '83 CP (pg. 60)

5. Explore the possibility of using the Good Samaritan Act to limit liability of child restraint loaner programs as well as manufacturers whose products meet legal standards.

6. Develop and/or support legislation to include HIB vaccine with other vaccines required for school entry.

9. Initiate consistent legislation that sets minimum standards for pool and playground areas built and/or maintained by local departments of parks and recreation, local school systems and day care and preschool centers. Suggest that the Virginia Health Department be the lead agency. '83 MCH (pg. 25)

SCHOOL AGE:

3. Establish and enforce, with lead by the Virginia Department of Education, minimum standards for health services in the schools. Require qualified nursing personnel in all school in ratios which conform to national standards. MCH (pg. 24)

5. Encourage the Virginia Department of Health, Virginia Department of Education and Virginia Department of Transportation to develop programs and legislation aimed at the prevention of head injury especially in children and adolescents. Such programs would be focused on the use of bicycles, ATVs, skateboards and mopeds as well as playground injuries. CP (pg. 60) MRP (pg. 57) MCH (pg. 24/25)

6. Make primary health care facilities accessible to all teens including attention to physical and mental health needs. MRP (pg. 57) MCH (pg. 24/25)

7. Establish a suicide/crisis program in each school system to provide support, intervention, and prevention services for students, teachers and families. Train staff and personnel for such programs in youth suicide and base the training on valid research data in reference to the National Suicide Center. CP (pg. 9)

8. Make age-appropriate programs for supervision of children available and accessible (funding, transportation, etc.) for those families needing

them. Involve public and private resources in implementation and focus on both educational and recreational needs. **CP (pg. 31) MRP (pg. 57)**

10. Establish and enforce minimum standards by the Virginia Department of Health and the Department of Education for prevention of sports and playground injuries in schools and the community. **'83 MCH (pg. 24/25)**

13. Mandate for all localities multidisciplinary teams whose focus is to include case consultation and coordination of assessments, treatment, and follow-up services for child abuse/neglect.

20. Encourage use of Child Study Teams with input of teachers, guidance, special education, etc., as vehicle for early intervention for children with problems. Encourage intense language programs in kindergarten. Encourage heterogenous grouping of students.

21. Encourage Child Study Teams to keep minutes of their meetings with log system of educational strategies used for students with problems.

23. Encourage ongoing communication and cooperation between special education teachers and regular teachers in order to improve the planning of educational services for developmentally disabled or high risk students.

27. Continue to support the Statewide Systems Project for mainstreaming.

28. Promote school breakfast programs.

EDUCATION RECOMMENDATIONS

GENETICS:

2. Mandate and fund a masters level genetic counseling program to address manpower needs in Virginia. This should include funding and FTEs for at least three faculty positions and student stipends which require students to provide services in the state for a specified time.

5. Fund a full-time educator at each state genetic center to educate a variety of audiences about genetic disorders. This funding must include necessary educational materials. **MCH (pg. 35)**

6. Fund a program for education of health professionals and patients concerning risk of birth defects resulting from maternal conditions such as diabetes, seizure disorders, and metabolic disorders. **'83 CP (pg. 1/2/26/27)**

9. Fund post-doctoral training in clinical genetics at each state human genetics center.

10. Include human genetics education materials as a component of Family Life Education curricula. **MCH (pg. 36)**

16. Improve phenylketonuria (PKU) education and follow-up directed toward both health professionals and female patients, especially with regards to risk to offspring from maternal PKU. **'83**

17. Fund a teratogen information and research program. MCH (pg. 35)

PERINATAL:

3. Fund preconceptional education and treatment programs, included with Title X/State Family Planning money, to discourage the use of any addictive substances and to encourage cessation from substance use prior to conception.

6. Provide education and incentives to all perinatal health care providers to screen all pregnant women for high risk conditions which may affect pregnancy outcome, including infections, substance use, inadequate nutrition, sexual and physical abuse, environmental stress, health problems.

7. Fund adequate evaluation of Family Life Education throughout the state and identify and promote the replication of successful curricula and programs.

8. Promote contraception education with emphasis on teenage males and their responsibilities for pregnancy prevention and for their children. **'83**

9. Support the Virginia Perinatal Association's Preterm Birth Prevention Program statewide. **'83**

15. Encourage marketing by local health departments of availability of free pregnancy testing and preferred sources of pregnancy test counseling. **'83**

17. Ensure adequate attention to developmental disability prevention in components of Family Life Education (FLE).

18. Support specific FLE curriculum regarding fetal effects of substance use and abuse beginning in grades four, five, and six.

20. Require alcohol warning posters focusing on fetal alcohol effects displayed prominently in retail outlets for alcohol sale (stores, restaurants). **'83**

EARLY CHILDHOOD SUB GROUP I:

13. Establish one central location which stores, for public use, legislation and regulations relevant to children zero to five years.

EARLY CHILDHOOD SUB GROUP II:

2. Mandate training for professionals and persons, eg. child protective service workers and foster and adoptive parents, working with or caring for children to: (a) enable them to identify child abuse and neglect, including risk factors; and to (b) meet the special needs of children who have been abused and neglected. **'83 CP (pg. 40) MRP (pg. 40)**

6. Conduct a public awareness campaign to include law enforcers, health professionals, legislators and social service professionals that addresses:

(a) nature of the problem of lead poisoning,
(b) need for lead screening, and
(c) availability of lead screening.
MRP (pg. 40)

14. Conduct a public awareness campaign on relationship between the child abuse and neglect and child development.

EARLY CHILDHOOD SUB GROUP III:

3. Encourage the adjustment of child restraint public education to include proven behavior modification programs. **MRP (pg. 40)**

7. Designate regional poison control centers to be identified by the Virginia Health Department. Ensure those centers provide primary prevention of child poisonings and outreach education. Ensure outreach education includes efforts 1) to reach every family with young children, 2) to increase recognition of poison hazards, 3) to make poison control center readily accessible, 4) to place syrup of ipecac in each home and 5) to stress dangers of prenatal exposure to toxins in general and carbon monoxide in particular. **'83 CP (pg. 26) MRP (pg. 40)**

8. Initiate public and professional education programs which recognize unintentional injury as a leading cause of death and disability by emphasizing primary prevention of unintentional injury in children. **CP (pg. 61) MRP (pg. 40)**

SCHOOL AGE:

2. Promote comprehensive and accessible parent educational programs which help parents understand childhood development in order to promote children's healthy sexuality and prevent substance abuse, childhood injury, child abuse, and risk-taking behaviors. Establish local or regional resource centers for parents with appropriate information in using understandable language . **'83 CP (pg. 19/30) MRP (pg. 33/34/39)**

4. Support and evaluate data collected in the Virginia Board of Education's Family Life Education mandate. Emphasize improved training of professionals/teachers in how to teach all aspects of Family Life Education. **CP (pg. 21)**

5. Encourage the Virginia Department of Health, Virginia Department of Education and Virginia Department of Transportation to develop programs

and legislation aimed at the prevention of head injury especially in children and adolescents. Such programs would be focused on the use of bicycles, ATVs, skateboards and mopeds as well as playground injuries. **CP (pg. 61) MRP (pg. 40)**

7. Establish a suicide/crisis program in each school system to provide support, intervention, and prevention services for students, teachers and families. Train staff and personnel for such programs in youth suicide and base the training on valid research data in reference to the National Suicide Center. **CP (pg. 9)**

9. Enforce the Virginia Department of Education's certification standard requiring trained CPR/First Aid providers in each school and expand it to include training for all school personnel.

11. Train teachers, service providers and all other persons with direct contact on working with children who have suffered child abuse. **'83 CP (pg. 40)**

12. Ensure that all teachers receive a certain number of hours in special education training initially and as a prerequisite for future teacher certification. This should be required for certification and recertification of all teachers.

14. Mandate a parenting course for high school graduation requirements. **CP (pg. 19)**

15. Develop more education and service program stressing male involvement and responsibility in all reproductive issues. **CP (pg. 20)**

16. Develop special programs designed for children who are mentally retarded in regard to reproductive issues with the lead by the Virginia Department of Education. **CP (pg. 22)**

17. Develop public awareness programs and offer motivational programs to promote an understanding of misuse of legal and illegal substances and to change behavior. Include programs for substance abusing parents to assist them in breaking the cycle. **CP (pg. 22) MRP (pg. 33/34)**

18. Train all persons providing services to teens on the developmental stages and thought-process of teenagers.

19. Encourage religious institutions to provide family life education within their programs.

22. Encourage local educational authority to improve instructional strategies via regional State Department of Education workshops and visitations of model school divisions.

24. Encourage individualized instruction for all students in least restrictive environment; encourage utilization of research dealing with instructionally effective schools.

25. Retain the behind the wheel component of driver's education.

26. Encourage the Virginia Department of Youth Services to provide appropriate family life education for <u>all</u> of its clients. **CP (pg. 22)**

RESEARCH RECOMMENDATIONS

GENETICS:

3. Fund Virginia Congenital Anomalies Reporting and Education System (VACARES) as a line item in the state budget. This should include initial funding for at least five FTEs for additional manpower needs and continued evaluation for the program. '83

13. Fund a pilot study of neonatal screening for congenital adrenal hyperplasia (CAH) to be conducted by the state laboratory.

17. Fund a teratogen information and research program.

PERINATAL:

4. Support coordinated statewide data collection regarding sexually transmitted diseases and pregnancy and identify current practices of prenatal screening for infections in private, public, and academic settings. **MCH (pg. 13/14)**

7. Fund adequate evaluation of Family Life Education throughout the state and identify and promote the replication of successful curricula and programs.

13. Determine the extent of follow-up of women negative on testing for rubella antibodies and encourage immunization postpartum.

23. Support the Infant Death Study and use of the study to plan service delivery and education to reduce low birth weight and preterm births. **MCH (pg. 14)**

EARLY CHILDHOOD - SUB GROUP II:

4. Compile and summarize empirical evidence regarding predictors on: (a) dysfunctional parenting skills, (b) relationship between dysfunctional parenting skills and developmental disabilities, and (c) degrees of effectiveness of various intervention approaches.

EARLY CHILDHOOD - SUB GROUP III:

4. Initiate research to identify the incidence of morbidity in relation to unintentional injury (specifically, rate of incidence of unintentional injury among developmental disability population; rate of unintentional injuries among children with developmental disability parents; rate of unintentional injuries resulting in developmental disabilities). **CP (pg. 60)**

SCHOOL AGE:

1. Expand the study of the validity of programs directed towards prevention of risk taking behaviors such as substance abuse. Such programs include decision-making skills, role modeling, and peer educators. Expand and continue to fund those programs with proven validity. **CP (pg. 6) MCH (pg. 24)**

4. Support and evaluate data collected in the Virginia Board of Education's Family Life Education mandate. Emphasize improved training of professionals/teachers in how to teach all aspects of Family Life Education. **CP (pg. 21)**